INFORMATION NEEDED FOR REPORTING

Reporting Formats

Cancer cases may be reported using one of the three following formats. Submissions must be accompanied by a **Texas Cancer Registry Transmittal Form (TCR #2)**. Please refer to *Appendix C* for instructions on completing this form and for an original transmittal form to make copies from.

1. Confidential Cancer Reporting Form (TCR #1): The Confidential Cancer Reporting Form (TCR #1 revised March 2001) is one format that may be used to report your cancer cases. Examples of completed abstracts are shown in *Appendix D*. It is recommended that an alphabetic file of the reported cases be maintained by **your facility** in order to prevent duplicate case reporting.

   NOTE: *The revised confidential cancer reporting form **MUST** be used for **ALL** 2001 and forward cases.*

2. SANDCRAB Lite (SCL): SCL, a cancer abstract reporting software developed for non-electronic reporters, is available free of charge. Cases are entered directly into the computer and submitted to the TCR on diskette, thus eliminating the need for paper abstract forms. SCL meets TCR reporting requirements but does not meet all ACoS requirements for a cancer program. Contact the Central Office in Austin at 1/800-252-8059 or 512/458-7523 to request your copy of the SCL software or if you have questions regarding the software.

SCL 4.0 system requirements are:

* A 300 MHZ or Pentium based personal computer
* 32 MB or more RAM
* CD-ROM Drive
* Windows 95, Windows 98 or Windows NT
* 1.44 MB 3 ½" floppy drive
* Approximately 20 MB (20,000,000 bytes) of Free Hard Disk Space is needed to install the SCL program. Additional disk space will be needed as records are added to the database.

  NOTE: *Double sided/Double density 360K and 720K floppy diskettes are **not** acceptable.*

3. Electronic Data Files: Should follow the NAACCR format standards on page 16.

   Computer Modem: Contact the Central Office in Austin at 1/800-252-8059 or 512/458-7523 for details on submitting by modem or visit our web site at www.tdh.state.tx.us/tcr. Individual arrangements must be made for modem transmissions and transmittal forms, must be faxed to the central office at (512) 458-7681.

Information Needed for Reporting, continued

> **NOTE:** *Files may now be submitted via e-mail, but the files **MUST** be encrypted with a password. The reporting facility will need to contact the central office with the password.*

Format Standards

The layout and coding scheme for Reporting Formats 2-3 should follow the NAACCR's Data Exchange Record Layout. Please refer to the NAACCR Standard for Cancer Registries - Volume II for a description of the layout. All columns without data must be blank. All cases diagnosed prior to January 01, 2001 may be submitted in NAACCR version 7.0, 8.0 or 9.0. All cases diagnosed on January 01, 2001 and forward **must** be reported in NAACCR version 9.0. Submissions in an incorrect format, with missing or incomplete data, or with an unacceptable level of errors will be returned to the reporting facility. If cases are returned to your institution, they will not count towards your compliance.

> ***NOTE:*** *When using vendor software packages, follow the coding instructions specific to that software. Do not mix codes from one software package to another. Any alteration or deviation from the codes specified in the software instructions will create errors in reporting. For questions regarding coding, call your appropriate TCR regional staff.*

Each diskette submitted **must** have a **label** affixed with the following:

- name of reporting institution
- number of cases included
- reporting period
- software utilized (i.e., CANSUR/FACS, CNET^2, MRS, ERS, ELM, ONCO, SCL) and
- format type (1.44 MB)

Initial Acceptance of Electronic Data

To assess compatibility of submissions, a test file containing at least 50 records must be forwarded to the TCR. After evaluation of the file, the reporting institution will receive notification of the results. If compatibility is assured, please call the TCR to set up a schedule for regular automated submissions.

Timeliness of Data Submission

Collecting timely cancer data is an important function of the TCR. Researchers, epidemiologists, health planners, clinicians, and lay persons benefit from speedy access to the most current information. Given the current state of patient medical records and the **reporting requirements** of CDC, the TCR requires all cancer cases be submitted to the TCR within ***six months*** **of the initial diagnosis date**, or if diagnosed elsewhere, ***six months*** **from the date of admission**.

Information Needed for Reporting, continued

Timeliness of reporting is important, however, data quality and completeness must not suffer. All reports of cases shall be submitted to the department within six months of initial diagnosis or admission at their facility for the diagnosis or treatment of cancer (Texas Cancer Incidence Reporting Law and Rules, page 9, When to Report, a). Training on appropriate reporting procedures will be provided through your regional office as needed.

Data Submission Procedures

Submissions of data (paper forms or electronic) to the TCR must be *monthly, bi-monthly,* or, *at the very least, quarterly,* depending on the size of your institution and caseload. Contact your regional program manager to arrange quarterly submissions. **ALL** submissions must include a completed **Transmittal Form** (refer to *Appendix C* for instructions in completing the transmittal form) specifying the hospital name, address, date of submission and number of cases reported per year.

Reporting forms are to be batched by year of admission and mailed to the appropriate **TCR regional office**. The forms are to be mailed in **sealed, double** envelopes marked "**CONFIDENTIAL"**.

> ***NOTE:*** *To protect patient confidentiality and to avoid loss of forms/diskettes in the mail, it is* ***strongly recommended*** *that* ***any*** *confidential information sent to the TCR be mailed via registered or certified mail. The TCR will also use registered or certified mail to send confidential information to reporting institutions.*

All facilities reporting **electronically** must send the **diskettes** or files to the **Central Office** in **Austin**. The diskettes along with a **transmittal form**, must be mailed in mailers appropriate for electronic media and marked **"CONFIDENTIAL"**. For electronic file submissions via modem contact the Central Office in Austin at 1/800-252-8059 or 512/458-7523 for details or visit our web site at www.tdh.state.tx.us/tcr. Contact the Central Office in Austin for electronic file submissions via e-mail.

> **NOTE:** *Fax the transmittal form to the Central Office in Austin for both modem and e-mail submissions. Fax number (512) 458-7681.*

For facilities with an ACoS Commission on Cancer approved program, the ROADS manual as well as the TCR's Cancer Reporting Handbook is to be utilized to assure reporting compliance with **both entities** because the data sets for the TCR and ACoS are different. Please refer to *Appendix L* for a comparison of data sets for the ACoS, NAACCR, SEER, and TCR.

Information Needed for Reporting, continued

Please submit your data to the appropriate address as determined by the location of your institution. A map of the PHRs is located in *Appendix F*.

Public Health Regions 1,9,10 Kimberly Kinney-Lara, RHIT, CTR Program Manager Texas Department of Health Cancer Registry Division Public Health Region 1 1109 Kemper Lubbock, Texas 79403 806/744-3577 Fax # 806/767-0420 Email: kimberly.kinney@tdh.state.tx.us	**Public Health Regions 5,6** Judy Spong, MS, CTR Program Manager Texas Department of Health Cancer Registry Division Public Health Region 6 5425 Polk Street, Suite J Houston, Texas 77023-1497 713/767-3180 Fax # 713/767-3193 Email: judy.spong@tdh.state.tx.us
Public Health Regions 2,3,4 Elaine Allgood, CTR Program Manager Texas Department of Health Cancer Registry Division Public Health Region 2/3 1301 South Bowen Rd., Suite 200 Arlington, Texas 76013-1869 817/264-4590 Fax # 817/264-4597 Email: elaine.allgood@tdh.state.tx.us	**Central Office*** **Public Health Region 7,8,11** Annette Vandewerken, M.S., R.D., L.D. Texas Department of Health Cancer Registry Division 1100 W. 49th Street Austin, Texas 78756 512/458-7523 or 1/800-252-8059 Fax # 512/458-7681 Email: annette.vandewerken@tdh.state.tx.us ***ALL electronic submissions must be sent to the Central Office.** ***Please note: PHR 8 and 11 is now handled administratively by PHR 7**.

Casefinding and Reportable List 2001 (ROADS pgs. 5-6, 15-16) (SEER pgs. 5-7)

The Texas Cancer Incidence Reporting Act (Chapter 82, Health and Safety Code) requires every general and specialty hospital, clinical laboratory, and cancer treatment center to submit an abstract for each reportable diagnosis. Every **inpatient** and/or **outpatient** case (includes foreign patients) with **active disease** or **receiving cancer-directed therapy** must be reported to the Texas Department of Health **regardless of the state or country of residence**.

A disease index including both inpatient and outpatient cases should be obtained, after records for a given time period are complete and coded (i.e., monthly or quarterly). (See appendix M page M-1 for the required format). This list should be checked against a list of patients previously reported to the TCR in order to find new cases. Each medical record that was identified on the disease index should be reviewed for reportability. An abstract should then be completed for patients found on the disease index with a reportable cancer who have not previously been reported to the TCR. **Patients who have been previously reported to the TCR must be checked for subsequent possible multiple primaries.** Please refer to the *Criteria for Determining Multiple Primaries* in *Appendix G* and H for assistance.

> ***NOTE:*** *For institutions reporting by SCL and forms, contact your TCR regional program for an up-to-date listing of cases you have reported.*

Other department logs/records (radiation therapy logs, emergency room logs, oncology unit records, surgery logs, etc.) are to be reviewed in the same manner as the disease index to assure all reportable cases are submitted to the TCR.

Pathology reports, including all histology, cytology, hematology and autopsy reports, are to be reviewed to identify all reportable neoplasms. These should also be compared against a list of records submitted to the TCR to avoid reporting duplicates. Be sure to check for **multiple primaries** if you find a patient was previously submitted to the TCR. If in doubt, contact your regional office.

Outpatient laboratory, x-ray and CAT scan reports are to be reviewed to assure that all reportable cases are submitted to the TCR. Please use the following guidelines to determine reportability:

> ***EXAMPLES:***
>
> 1. The Final Diagnosis on the Discharge Summary states cancer and the ICD-9 billing code indicates current disease. No CT's, bone scans, or lab work were done at your facility. This case would be reportable.
>
> 2. The diagnosis on the face sheet states prostate cancer and the patient had a bone scan which is negative, the reportability of this case is dependent upon the reason for the bone scan. If it was to determine the stage of the current prostate cancer, it is reportable. If the prostate cancer was treated and the physician is doing routine screening for recurrence and the CT is negative then it is not reportable. If the reason for the bone scan cannot be determined then this case would not be reportable based on the negative bone scan.
>
> 3. The discharge summary and face sheet state history of cancer and there is no other information within the chart to indicate active or stable disease, then this case would not be reportable.
>
> ***NOTE:*** *Remember that physicians may refer to patients diagnosed with cancer prior to coming to your facility as having "history of " cancer. These cases should be reviewed closely to determine if the patient has active disease and/or is receiving cancer-directed treatment. If you have any questions regarding the reportability of a case call your regional program manager.*

Casefinding and Reportable List 2001, continued

The following list is intended to assist in identifying reportable cases. ICD-9-CM codes that are used to identify reportable neoplasms are on the left.

Codes and/or terms that have new malignant behavior codes in ICD-O-3 are **underlined** and the ICD-O-3 code is placed in **parentheses** following the terms.

ICD-9-CM Codes	**Diagnosis (in preferred ICD-O-3 terminology)**
042	AIDS (review cases for AIDS-related malignancies)
140.0 - 208.9	Malignant neoplasms
203.1	Plasma cell leukemia (9733/3)
205.1	Chronic neutrophilic leukemia (9963/3)
225.0 - 225.9	Benign & Borderline Neoplasms of Brain and Central Nervous System
230.0 - 234.9	Carcinoma in situ
235.0 - 238.9	Carcinoid, NOS (excluding appendix, unless stated to be malignant) Neoplasms of uncertain behavior
238.4	Polycythemia vera (9950/3)
238.6	Solitary plasmacytoma (9731/3)
238.6	Extramedullary plasmacytoma (9734/3)
238.7	Chronic myeloproliferative disease (9960/3)
238.7	Myelosclerosis with myeloid metaplasia (9961/3)
238.7	Essential thrombocythemia (9962/3)
238.7	Refractory cytopenia with multilineage dysplasia (9985/3)
238.7	Myelodysplastic syndrome with 5q- syndrome (9986/3)
238.7	Therapy-related myelodysplastic syndrome (9987/3)
239.0 - 239.9	Neoplasms of unspecified behavior
273.2	Gamma heavy chain disease; Franklin's disease
273.3	Waldenstrom's macroglobulinemia
273.9	Unspecified disorder of plasma protein metabolism (screen for potential miscodes)
284.9	Refractory anemia (9980/3)
285.0	Refractory anemia with ringed sideroblasts (9982/3)
285.0	Refractory anemia with excess blasts (9983/3)
285.0	Refractory anemia with excess blasts in transformation (9984/3)
288.3	Hypereosinophilic syndrome (9964/3)
289.8	Acute myelofibrosis (9931/3)

Casefinding and Reportable List 2001, continued

Admissions with the following treatment codes must also be checked for reportability:

V07.3	Other prophylactic chemotherapy (screen carefully for miscoded malignancies)
V07.8	Other specified prophylactic measure
V10.0 - V10.9	Personal history of malignancy (review these for recurrences, subsequent primaries, and/or subsequent treatment)
V58.0	Admission for radiotherapy
V58.1	Admission for chemotherapy
V66.1	Convalescence following radiotherapy
V66.2	Convalescence following chemotherapy
V67.1	Radiation therapy follow-up
V67.2	Chemotherapy follow-up
V71.1	Observation for suspected malignant neoplasm
V76.0 - V76.9	Special screening for malignant neoplasm

- **Squamous Intraepithelial Neoplasia M-80772, grade III of vulva (VIN), vagina (VAIN), and anal (AIN) (ICD-9-CM: 184.4, 233.3, 230.6; ICD-O-: C51.9, C52.9 and C21.0) Beginning with 2001 cases WILL be reportable to the TCR.**

All cases with a behavior code of "2" or "3" in the *ICD-O-2 for cases prior to January 01, 2001 and ICD-O-3 for cases January 01, 2001 and forward* are reportable neoplasms. Neoplasms of the brain and central nervous system with behavior codes of "0" or "1" continue to be reportable to the TCR

.

*Malignant neoplasms of the skin of genital sites **are** reportable. These include: vagina, clitoris, vulva, prepuce, penis, and scrotum (ICD-9CM: 184.0, 184.3-.4, 187.1-.4, 187.7; ICD-0: C51.0-51.9, C52.9, C60.0, C60.9, C63.2).

*Reportable Skin Tumors such as adnexal carcinomas (e.g., carcinomas of the sweat gland, ceruminous gland, and hair follicle), adenocarcinomas, lymphomas, melanomas, sarcomas, and Merkel cell tumor must be reported regardless of site. Any carcinoma arising in a hemorrhoid is reportable since hemorrhoids arise in mucosa, not in skin.

Pilocytic/juvenile astrocytoma M-9421 which changed from /3 to /1 will CONTINUE to be collected as a /3.

The following are **exclusions** and need **not** be reported:

8000-8004	Neoplasms, malignant, NOS of the skin (ICD-9CM: 173.0-.9; ICD-O: C44.0-.9)
80102	Carcinoma in-situ of the cervix (regardless of histology) (ICD-9-CM: 233.1; ICD-O: C53.0-1, C53.8-9) **beginning with 1996 cases**.
8010-8045	Epithelial carcinomas of the skin (ICD-9CM: 173.0-.9; ICD-O: C44.0-.9)
8050-8084	Papillary & squamous cell carcinomas of the skin (ICD-9CM: 173.0-.9; ICD-O: 44.0-.9)
80772	Squamous Intraepithelial Neoplasia, grade III of cervix (CIN) (ICD-9-CM: 233.1; ICD-O: C53.0-1, C53.8-9) **beginning with 1996 cases**.
8090-8110	Basal cell carcinomas of any site **except genital sites ***
8148	Prostatic Intraepithelial Neoplasia (PIN III) M-8148/2 will NOT be collected by the TCR.

Casefinding and Reportable List 2001, continued

- **Borderline cystadenomas M-8442, 8451, 8462, 8472, 8473, of the ovaries which changed from /3 to /1 will NOT be collected as of January 01, 2001.**

Cases in which the disease is **no longer active** should only be reported if the patient is still receiving cancer-directed therapy, (i.e., leukemia in remission receiving chemotherapy).

For Newly Reportable Hematopoietic Disease (NRHD), which are any of the myeloproliferative or myelodysplastic diseases that changed from /1 borderline to /3 malignant in ICD-O-3, report only new NRHD cases diagnosed January 01, 2001 and forward. If disease was diagnosed prior to January 01, 2001 do not report.

> **EXAMPLE:** Patient with acute myelosclerosis diagnosed in May 2000, comes to your facility in 2001. Currently receiving blood transfusion once per month. Since acute myelosclerosis was not reportable in May 2000 this would not be a new case and therefore not reported to the TCR.

Disregard NRHD cases diagnosed prior to January 01, 2001 undergoing active treatment.

> **EXAMPLE:** Patient with idiopathic thrombocythemia diagnosed in November 1999, admitted to your facility in 2001. Patient comes in every 8 weeks for chemotherapy. Since idiopathic thrombocythemia was not reportable in 1999 this is not a new case and would not reported in 2001 to the TCR.

Compare diagnoses to check for transition to another hematopoietic disease. Use the ICD-O-3 hematopoietic primaries table to determine whether patient has a single primary or more than one.

> **EXAMPLE:** Patient comes to your facility 03/20/2001 with polycythemia vera diagnosed 1997, intractable to phlebotomy. Received P32 in 2000. Bone marrow biopsy 03/20/2001 shows refractory anemia. Per hematopoietic table, these are 2 primaries. Do not report polycythemia since it was not reportable in 1997, refractory anemia is now reportable in 2001 and needs to be reported to the TCR.
>
> **NOTE:** The hematopoietic primaries table from the TCR Handbook April 2000 and from the TCR Handbook April 2001 are not to be used interchangeably.

For a diagnosis that uses ambiguous terms, the following guidelines should be used:

Diagnostic of Cancer: apparently, appears to, comparable with, compatible with, consistent with, favor(s), malignant appearing, most likely, presumed, probable, suspect(ed), suspicious and typical (of/for) are considered to be diagnostic of cancer.

Exception: If cytology is reported as "suspicious" do not interpret this as a diagnosis of cancer. Abstract the case only if a positive biopsy, a physician's clinical impression of cancer supports the cytology findings, or cancer directed therapy is administered.

Non Diagnostic of Cancer: approaching, cannot be ruled out, equivocal, maybe, possible, potentially malignant, questionable, rule out, suggests, very close to, and worrisome. **Report these cases only if cancer-directed therapy is planned or given.**

When phrases such as "strongly suggestive" or "highly suggestive" are used, disregard the modifying phrase and refer to the guidelines above regarding the primary term.

Additional Guidelines for Case Reporting
Patients with a history of cancer, with no evidence of active disease, should **not** be reported unless they are receiving cancer-directed therapy.

> **NOTE**: *Stable disease indicates active disease*

Casefinding and Reportable List 2001, continued

EXAMPLES:

A patient is admitted for evaluation of congestive heart failure who had a mastectomy for breast cancer 8 years ago with no evidence of recurrent or metastatic disease. This patient has no evidence of ***active*** *cancer and should not be reported.*

A patient was diagnosed with adenocarcinoma of the stomach in 1985 with no evidence of recurrent or metastatic disease. In 2001, the patient was admitted and diagnosed with small cell carcinoma of the lung. Report only the lung cancer, since the stomach cancer is ***not active****.*

A patient was diagnosed 6 months ago with acute myelocytic leukemia, now in remission, on a maintenance dose of chemotherapy. The patient was admitted for evaluation of neutropenia following the last course of chemotherapy. If this is the first admission to your facility, this patient should be reported because cancer-directed treatment (chemotherapy) is being administered.

Cases which were diagnosed and/or treated for cancer prior to admission to the reporting institution **are to be reported** if there is evidence that the patient still has **active disease**, whether or not diagnostic or therapeutic procedures were performed in the reporting institution.

EXAMPLE: *A patient is admitted to your hospital with an acute cerebrovascular accident. The H&P states the patient was diagnosed with metastatic lung cancer four months prior to admission. He was treated with palliative care and referred to the Hospice program. All indications are that this patient still has active cancer and should be reported to the TCR, regardless of whether diagnostic or therapeutic procedures were performed at your institution.*

Cases diagnosed at autopsy, with no suspicion prior to death that the cancer existed, are to be reported.

Cases are to be abstracted using the medical record from the first admission (inpatient or outpatient) to your facility with a reportable diagnosis. Information from subsequent admissions are to be used to supplement documentation as needed and appropriate and to encompass all first course treatment information.

Do not complete a report for each admission; submit one report per primary tumor.

EXAMPLES:

A patient is diagnosed with prostate cancer and has several admissions for treatment of the prostate cancer. Only one report is to be submitted.

A patient is diagnosed with two separate PRIMARY tumors, such as adenocarcinoma of the prostate and squamous cell carcinoma of the lung. Submit one report for the prostate primary and another for the lung.